

## FEATURE

## The Problem With Science—The Context and Process of Care: An Excerpt From *Remodelling Medicine*

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### Key Words

Scientificism, science, truth, illness, treatment, research, integrative medicine, healing, policy, whole person

### SUMMARY

- The goal of science is truth through knowledge. But medicine's truth is not altogether the same as science's truth.
- Science works with ideas, imagination and intuition, but essentially has to do with facts. Medicine has also to deal with meaning.
- This is not an argument for less science in medicine, but for more and better science; better in the sense of better attuned to 'the rest of life'.
- Truthfulness is a core principle of medical practice and medical science.
- But a kind of untruthfulness is common in day-to-day clinical practice.
- The fundamental untruth is the illusion of certainty.
- The inexcusable untruth is to reduce the patient's problem to it to its narrow biomedical parameters and to allow the patient as a person to vanish from our gaze.
- Science fails medicine by the narrowness of the scope of things it is willing to investigate. Important areas of medicine have been neglected as a consequence.
- The medical research culture must change if it is to promote science for understanding alongside science for manipulation. We need to be unsparingly critical of the distinction between useful science and wasteful science.
- "Medical knowledge is not knowledge acquired primarily for its own sake (but) for a specific purpose—the care of the sick."<sup>1</sup>

### SCIENTIFICISM

William James (1842–1910) was an American psychologist and philosopher best known for the series of Gifford lectures delivered in Edinburgh in 1901 and later published as *The Varieties of Religious Experience*. His work was reviewed in the BBC Radio 4 programme 'In our time' on the 13th of May 2010, when he was judged by one expert to have been the greatest philosopher ever! He did not draw any firm conclusions about the existence of God from his research, whose purpose was psychological rather than theological, and he was open to the possibility that some or all of those varieties of experience might be eruptions from the individual's subconscious. But he was insistent that they should be taken seriously, and was critical of the scientific attitude towards such phenomena, though he was primarily a Darwinian scientist himself who turned to philosophy in later life.

One of his criticisms is particularly pertinent to the problem of science in relation to medicine. He said that the worst thing about science is 'the religion of scientificism'—which induces a kind of fear. He said his fellow scientists crippled themselves by the fear of doing something that might be regarded as unscientific, and so they closed their minds. This is reflected in quotations from Kuhn and Polanyi in Chapter 11. James's view, consistent with Darwin's open-minded scientific attitude, was that we have to be open to the thought that what seems intellectually absolutely unavoidable today may seem really stupid to us tomorrow. So we

should never close down on any intellectual possibilities whatsoever. The quotation from George Engel that introduces Chapter 6 that the scientific attitude can permit no restrictions as to the category of natural phenomena investigated echoes the same conviction. The discussion on the radio went on to reflect on the ascendancy of Bertrand Russell's philosophy, and the triumph of what James would have regarded as an overinvestment in logic and a lack of interest in the diversity of human experience. This sentiment is echoed in the quotation from Mary Midgeley at the end of Chapter 6, which concludes, "We do not need to esteem science less. What we need is to esteem it in the right way. Especially we need to stop isolating it from the rest of life".<sup>2</sup> One of the speakers on the radio suggested that James' continuing importance is that he represents a struggle in his period and our own to reconcile naturalism, the understanding that human beings are the product of nature, with humanism; the struggle to find a place for human values in a world of nature. Which today might be represented as the question—in a world of particles, what place is there for values?

### SCIENTIFIC TRUTH IN MEDICINE

*The good internal to the practice of research is truth, an understanding of what is really real about some aspect of the world we inhabit.<sup>1</sup>*

The goal of science is truth through knowledge. Thus, the role of science in medicine is to get at the

truth. But medicine's truth is not altogether the same as science's truth. Science works with ideas, imagination and intuition, but essentially has to do with facts. Medicine has also to deal with meaning. In this, medicine comes close to theology. Science and theology are both exploring reality; different but inseparable aspects of reality. Medicine somehow has to accommodate the patient's whole reality. The truth we seek is "to understand things as they really are, knowing that in its fullness it will always be beyond us".<sup>3</sup> But if we abandon it we abandon our patient. And medicine's truth has to accommodate the diversity of human experience that an over-investment in logic may disregard. It has to accommodate 'the rest of life' of which our biomedical condition is only a part and a reflection. It has to accommodate the values that give meaning to the particles.

Medicine's problem with science has been a recurring theme throughout this book—a problem born out of success. The programme on William James also touched upon the fate of movements, of the spirit or of the mind, that become codified and institutionalised and suffer a loss of the life that inspired and motivated them. This is true of medical science to the extent that it has become increasingly concerned with manipulation rather than understanding; increasingly focused on the particles, and less on the rest of life. Our gratitude for the success of medical science in what it has been able to do for us need not be diminished by suggesting that it is seeking increasingly sophisticated answers to the wrong questions. Or rather that it is failing to address the right questions with the same degree of sophistication and commitment.

This is not an argument for less science. On the contrary, it is the same argument that David Horrobin made 30 years ago for more and better science.<sup>4</sup> That does not mean 'better' in the sense of more skilled or sophisticated, but in the sense of better attuned to 'the rest of life'. In Horrobin's terms it means making science more humane; more concerned, as he puts it, with the extraordinary potency of the control mechanisms that maintain the constancy of our physico-chemical equilibrium, without which we would never remain well. He is highlighting medical science's surprising lack of interest in this 'evolutionary imperative'; its preoccupation with learning to control the processes that go wrong at the expense of learning to enable the processes that help to put things right. And its lack of interest in learning to exploit them; even though they are integral and indispensable to every therapeutic process.

This is an argument that medical science needs to be better directed; better attuned to the humanistic rather than the mechanistic goals of medicine. It is a huge challenge to the culture of medical science; and to the culture of medicine in general. And to the culture of the society that medicine serves and helps to shape, and in turn is shaped by.

The wider cultural implications, such as medicine's role in creating the kinder, more imaginative, more generous world', 'the more just and sustainable

world' envisioned in the quotations in Chapter 4, are employed in Chapter 17. The essential cultural reorientation that is required of medical science is that it should 'frame its understanding of the world to understand the world truly rather than in order to control the world easily and cheaply.' That is a crude paraphrase of a quotation from an essay on medical knowledge by HT Engelhardt that is used by David Greaves in his analysis of the problem with science in *Mystery in Western Medicine*, which I warmly recommend.<sup>5</sup> The quotation is crude not only in the way I have rephrased it, but in the aspersion it casts on the goals of medical science; whose application in the real world is in any case seldom easy or cheap. But it makes the point yet again that the role of science is to understand the world *truly*.

Truthfulness, I have suggested, is a core principle of medical practice and medical science, and I outline my reasons in Chapter 10. But in fact, untruthfulness is common in day-to-day clinical practice.<sup>6</sup> It arises when medicine only acknowledges part of 'the story of sickness'. A diagnosis, for example, is only part of the story; a description of what is going on, rarely an explanation of why a thing is as it is, but often presented as if it defines the whole problem.<sup>7</sup> Untruthfulness arises when a doctor gives an antibiotic for a self-limiting illness, or another inappropriate prescription (though possibly with significant 'placebo' effect); or offers a diagnosis when the truth is 'I don't know'; or tells an ill patient there is nothing wrong because the tests are all normal.

Untruth is introduced when "the dogma of technological medicine ignores the therapeutic effect of the doctor and the self-healing powers of the patient"<sup>8</sup> when "doctors expect to find an answer to every problem if only they look hard enough with the right instruments."<sup>9</sup> It happens because although technology allows us to practise with ever greater precision and is a powerful tool for understanding, it also creates powerful misunderstanding when unwisely applied.<sup>10</sup>

In a great deal of medical practice, often with the best of intentions and to good effect, there is an element of deceit. This inherent untruthfulness is not necessarily to be condemned so much as to be acknowledged and reflected upon; sometimes to be corrected, sometimes to be accepted when there are mitigating circumstances.<sup>11</sup> Deceit and consent to deceit are inevitable in medical practice whenever we imply, and quite possibly believe, that we know the truth of the matter when all we really know are some of the facts of the matter. We are victims of the success of biomedicine because of the expectation it encourages that we have the answers; whereas we are always dealing with a high degree of complexity and uncertainty. The inherent truth of the patient's experience will often be beyond us. But that does not absolve us from the responsibility to be open to it, and faithful to it—as best we can be and as fully as the patient invites us to be.

The fundamental untruth is the illusion of certainty. The inexcusable untruth is to reduce the problem and our response to it to its narrow biomedical

parameters and to allow the patient as a person to vanish from our gaze. We can have no certainty about all that determines the course of illness and healing in any individual. We have to explore constantly and courageously that penumbra of uncertainty that surrounds our presumed certainties. This attitude does not displace, but assumes and comprehends proper respect for evidence and scientific method, clinical knowledge and skill. But it leaves room for the flexibility of mind that is essential if we are to know the world truly; especially if we are to open to the inherent truth of the patient's experience. This flexibility is not scientific *laissez-fair* but an honest acknowledgement that, to paraphrase John Polkinghorne, on the one hand the physical world is too surprising to allow any a priori concept of what is reasonable, and on the other, the actual character of our encounter with reality must be allowed to shape our knowledge and our thought.<sup>12</sup>

### THE LIMITATIONS OF SCIENCE

Science fails medicine not through lack of competence—it is able to do and to discover amazing things, but through lack of vision. Not for want of curiosity, but for the limit of things it is curious about. Not for any lack of the ability to investigate, but for the narrowness of the scope of things it is willing to investigate. The weaknesses of science are its strengths: its preoccupation with the things it does well and with the tools it knows how to use best. The opportunities of science to explore novel conceptions that do not sit comfortably with its contemporary paradigm seem to be regarded almost as threats; stifled by the fear that once a new framework is accepted it will lead to conclusions that have been hitherto, rightly or wrongly, abhorred (to paraphrase the quotation from Polanyi in Chapter 11); stifled by the quasi-religious fear of William James's 'scientificism'.

In short, science must be true to its traditional vocation to the systematic pursuit of knowledge that permits no restriction as to the category of natural phenomena investigated. The cultural and structural problems that contribute to this loss of vision are explored in the Introduction and in Chapters 10 and 11. The areas of medicine that have been neglected as a consequence, though not quite ignored, include the following:

### HEALING PROCESSES

We know a great deal about the causes of disease and the mechanism of the body's response to insult and disorder of various kinds; causes as precise as our genetic susceptibility; mechanisms analysed down to the cellular and intracellular level. We know a great deal about the detailed mechanics of bodily self-regulation. We know a certain amount about the influence of psychological and environmental factors on these processes. We can describe the healing of a wound by first and second 'intention', the restoration of biochemical measurements to 'the normal range', the change in certain pathognomonic symptoms (symptoms charac-

teristic of a specific disease). But our understanding of the correlation of these factors with the well-being of the person as a whole is more uncertain. Remember the quotation from Roy Porter:

*In myriad ways, medicine continues to advance, new treatments appear, surgery works marvels, and (partly as a result) people live longer. Yet few people today feel confident, either about their personal health or about doctors, healthcare delivery and the medical profession in general.<sup>13</sup>*

For example, we know perfectly well that the 'placebo' effect and contextual healing happen. We know that various factors can promote these effects. And we know that they account for a significant part of even the specific efficacy of treatments demonstrated in controlled trials, as well as their actual effectiveness in practice. But we have a very poor understanding of these fundamental dynamics of healing processes; let alone how to make best use of them.

We know very little about the natural history of these effects in the person as a whole. We know that placebo can induce relief of presenting symptoms, measurable physiological changes, and changes in brain chemistry. But the more general effect of these reactions in the person as a whole, and the effects over time are not known. We do not know anything much about the time scale of onset or duration of placebo responses, or their permanence or transience. We do not know to what extent they are usually limited to the target symptom or condition. We do not know whether and to what extent they have incidental effects on aspects of well-being other than the presenting problem. Bearing in mind that 'placebo' responses 'work' by mobilising resources for self-regulation and self-healing, we do not know whether these resources are thereafter enhanced to the benefit of longer term healthfulness. The only context I know, and to which I can find reference, in which detailed observations of this kind are made is the homeopathic method that I describe in Chapter 14 and Appendix 14.1.

A piece of research begging to be attempted, for example, is suggested by the short notes on 'Healing processes' in that chapter. The detailed observation of changes in response to treatment by the homeopathic method provides a well documented account of the dynamics of self-regulation and self-healing across a wide range of morbidity. These clinical observations, described in the appendix, are valid whether the agent of the healing process is the contextual or 'placebo' effect of the method, or the homeopathic prescription itself, or a combination of the two. A similarly detailed and documented account of placebo responses, in conventional trial situations perhaps, would permit comparison between the two sets of observations. Firstly, both would be descriptions of 'natural healing', providing invaluable insight into that process, because whatever they do homeopathic medicines cannot have

pharmacological effects. And secondly the comparison would cast light on the similarity or difference of the process in the two clinical situations, allowing us to draw inferences about the similarities or differences between the effect of the homeopathic medicines and the inert placebo agents used in trials.

## ILLNESS

We know a great deal about disease processes, but we do not know much about the poorly defined state that we call illness, and out of which disease arises; or from which medicine has to ‘create’ a disease in order to explain it. Actually, that is not quite true. It is more accurate to say that we do know a fair amount about the things that make us ill, but we can’t do much about it, unless and until it becomes a disease, or unless we can turn it into a disease we do know how to treat, or at least how to control. We know, for example, that exams, bereavement and moving house, and other critical or traumatic situations in life affect our immune system and our adrenal function. We know that poverty and social deprivation make us ill; not only when there is actual lack of essential food, accommodation, hygiene, education, etc., but also where there is relative lack of material well-being compared to wealthier sections of society. And the medical and social sciences do develop or advocate the means to remedy or mitigate such problems. But there is an inevitable element of mystery to personal illness, and to the challenge of meeting the needs of a particular individual who is ill.

It may be beyond the scope of science to analyse every facet of the mystery of personal illness. But at least it must not encourage us to neglect the mysterious in favour of the measurable—the McNamara fallacy again (Chapter 10). The science that permits us to define illness in terms of precise biological disorder must not distract us from the importance of the biographical diagnosis, the story of the sickness. But more importantly it must take account of that broader diagnostic perspective, explore it, and help us to understand and manage it.

However, there are questions that may shed light on aspects of the mystery that medical science can, and to a limited extent does answer:

- ‘*Why me?*’ Why do/did I become ill when others in similar circumstances did not?
- ‘*Why this?*’ Why did I develop this illness/disease? Why do I react to anxiety/hot weather/a virus with headache, when X gets diarrhoea and Y gets eczema?
- ‘*Why now/then?*’ Why did it happen when it did—not six months ago, or next week? What were the factors/circumstances that determined the time of onset?

The limited extent of medical science’s exploration of these questions is illustrated by contrast with the particularly detailed case taking necessarily employed by doctors using the homeopathic method.

This is a clinical process of a wholly conventional if unusually comprehensive kind that yields an unusually versatile and comprehensive synthesis of biological and biographical data from which, by contrast with a more conventional approach, a more complete understanding both of the evolution of the illness in that person (the story of sickness), and of what needs to be healed as well as treated can emerge.<sup>14</sup> This not only facilitates the therapeutic process, but also reveals the possible scope of detailed epidemiological enquiry.

## TREATMENT—THE BLACK BOX

For a period during my GP career my surgery was in our home. My consulting room was our sitting room out of hours. Patients would often sit on the sofa. The waiting room was a small room immediately adjacent where the receptionist sat with the patients, and the atmosphere was intimate, welcoming and cheerful. The sound of laughter filtering through the door into the consulting room, unusual in the average doctors’ waiting room, was not uncommon. I provided routine fifteen minute appointments, but the patients were often and evidently feeling better by the time they came in to me because of the warmth of their ‘reception’. They did then get the benefit of my repertoire of clinical skills, and whatever personal qualities I brought to the relationship. This, at the time, was my therapeutic ‘black box’. It would be quite difficult to itemise all of its component parts. And impossible to be sure which component made what contribution to the patient’s subsequent well-being and clinical outcome. A GP colleague of mine identified 35 separate components of the therapeutic encounter.

All treatment, every medical encounter is a therapeutic black box. The workings of the black box in conventional practice, we like to think, are less of a mystery because we know what the specific component, the drug or procedure is meant to do. The workings of the black box in complementary medicine are often represented as a sort of confidence trick because we are sceptical that it has a specific component that does anything at all. In either case the result may be effective or ineffective, safe or unsafe. But the medical model justifies the use of the black box only if it has a specific component whose efficacy can be ‘proved’.

One approach to the black box is to unpack it, isolate that specific component, and submit it to ‘destructive analysis’. Another approach is to say that we must not attempt to unpack the black box because to try may destroy it, and deprive it of its practical effectiveness.

Science has a dual responsibility towards the understanding of human wholeness and the healing vocation that is expressed beautifully in an essay by George Orwell on *The Meaning of a Poem*:

*I have tried to analyse this poem as well as I can in a short period, but nothing I have said can explain, or explain away, the pleasure I take in it. That is finally in explicable, and it is just because*

*it is inexplicable that detailed criticism is worthwhile. Men of science can study the life-processes of a flower, or they can split it up into its component elements, but any scientist will tell you that a flower does not become less wonderful, it becomes more wonderful, if you know all about it.*<sup>15</sup>

Science must combine a humility and sense of awe in the face of the wonderful and inexplicable, and in the face of irreducible uncertainty, with a scientific passion and insatiable curiosity to know all about it. It will never fully explain, and must never seek to explain away, the mystery of life, but the mystery itself makes critical analysis worthwhile.

Medical science must accept that there is always a black box that operates between every practitioner and every patient in every therapeutic encounter. It has many components and many dimensions, and the permutation of these will vary from one encounter to another. The complete and precise operation of the black box, the outcome of its operation, its effectiveness, the human consequences, will always, ultimately defy analysis. That finally is inexplicable, and it is just because it is inexplicable that detailed criticism is worthwhile.

Medical science must not make the mistake of confusing the question whether the black box ‘works’, with the question how it does it. Both are valid questions, and both have valid answers. Both are worth exploring. But the answer to one does not depend upon the answer to the other. We would like to know how our black boxes ‘work’, and we will try to find out. But what matters more is that they do work. If we are honest, and admit, as research into placebo effects increasingly reveals, that all our therapeutic activities are effectively black box operations; and if we were to abandon all treatments in which we do not fully understand how the black box works, we would give up medical practice altogether.

#### USEFUL SCIENCE AND WASTEFUL SCIENCE

Useful science enables us to do things that are really worth doing. The question of what is really worth doing is an ethical and cultural question that is profoundly important to our conception of the goals of medicine and the model we devise to serve those goals. But we have seen in Chapter 9, when exploring the crisis of cost in the health service, that when challenged to reduce cost there is a considerable number of activities that clinicians consider are not worth doing. Medical science has made it possible to do them and provided the technology to do them. This bears out Lyng’s suggestion quoted in the earlier discussion of the problems of technology in Chapter 11, that technology encourages ‘the interventionist thrust’ of modern medicine. This appetite for and tacit dependence on the necessary ‘instrumentation’ is fed by medical science, and rather than serving the goals of medicine simply ‘creates the space for possible medical events.’<sup>16</sup> David Horrobin characterised this over-use of technol-

ogy as “The application of a technique to a situation, without any critical consideration of whether the outcome is likely to be favourable or not”.<sup>4</sup> We might restate David Haslam’s observation that “We use the medical model because the medical is what we use, even though it may not be appropriate”,<sup>17</sup> as ‘We use medical technology because medical technology is what we use, even though it may not be appropriate.’

Science wastefully applied, because it is not really useful, is of course science harmfully applied. Every intervention carries some risk; is potentially iatrogenic. An intervention that is not really useful is one kind of medical untruth. And a wasteful intervention costs money that could be better spent.

In May 2010 the *British Medical Journal* published a ‘head to head’ debate, ‘Is modern genetics a blind alley?’<sup>18</sup> “Yes”, says James le Fanu. “Modern genetics has become the largest single research field in the history of biology, driven forward by the expectation that ‘like a mechanical army (it will) destroy ignorance . . . promising unprecedented opportunities for science and medicine’. And yet for all this cornucopia of new facts and knowledge, its influence on everyday medical practice remains scarcely detectable.” He quotes the chief executive of Genentech as saying that all this effort amounts to “the largest money losing industry in the history of mankind.” He speculates that the complexities of those methodologies might explain in part the paucity of original ideas in medicine, diverting attention and resources from more fruitful forms of clinical research. Le Fanu regards it as “highly improbable that the future of medicine might lie in understanding disease at (this) most fundamental reductionist level.”

D.J. Weatherall argues that on the contrary genetic research promises real benefits and is already delivering some. He points out that genetic research is a young discipline and that it would be short sighted to view it as a blind alley, considering the complexity of the subject it has to explore. But his contribution to the debate does not inspire confidence. He acknowledges the extraordinary complexity of biological function in health and disease that modern genetics continues to unearth. He compares this phase of its exploration to the endless, and some might argue similarly fruitless search in modern physics for a grand unifying theory. He acknowledges that most common diseases “seem to reflect the action of many different genes with small effects, presumably combined with environmental factors and the biology of ageing.”

Research like this is presumably driven by scientific passion, and does increase our wonder at the beautiful intricacy of life, even if ultimately what makes us tick remains inexplicable. But having read this debate, I wonder to what extent the research will prove to be practically useful. Nevertheless, it is reassuring that this debate, and the ethical debates about embryo research and the like, are happening.

But science has a huge responsibility to be sure that its passion and the seductive power of what it can do, do

not lead us up blind alleys, at the end of which nothing really useful is achieved; particularly if our essential humanity and wholeness is diminished in the process.

## RESEARCH

Perhaps the most serious revolution that remodelling medicine requires is in medical research. There are many challenges (see Box 18.1). The predominant thrust of research programmes is to isolate a problem from its ‘confounding variables’ (all the other things in life that bear upon the health and well-being of the afflicted person), and then to reduce the problem to its most fundamental biological component (genetic, biochemical, functional, anatomical) so that this can be managed or manipulated. The test of the ability of any treatment that results from this process to do what is expected of it (its efficacy) requires that the measurement of this outcome is similarly isolated from the effect of confounding variables.

### BOX 18.1 Research Challenges

- The dynamics of illness.
- Healing processes.
- Enabling self-regulation.
- Context and meaning.
- ‘Subtle’ therapeutic effects.
- The therapeutic ‘black box’.

This is a generalisation that is not true of all research methods, but it does represent the principal focus and predominant thrust of medical research. It is brilliantly successful in what it sets out to do. It does make it possible to manage or manipulate particular components of disease processes. But it provides a very partial solution to the whole complex spectrum of illness-disease-sickness. I have hyphenated the three words to emphasise that medicine is concerned with a complex phenomenon of which the pathology, which is what we usually mean by disease, is only a part. The illness-disease-sickness triad, whose various meanings are discussed at the beginning of Chapter 8, involves the person as a whole and is contingent upon a multiplicity of circumstances in the person’s life. What is more any medical intervention affects the person as a whole, not just the part that it acts directly upon, and has consequences for the circumstances of the person’s life. And lastly, no actual medical intervention is simple or circumscribed. As we have seen it is always a ‘black box’ procedure.

The narrow focus of biomedical research, for all its achievements, cannot do justice to this complexity. In fact it really has nothing to say about it. This is not to disparage biomedical science. It is not an argument to esteem science less, but ‘to esteem it in the right way’, in Mary Midgeley’s words; ‘especially to stop isolating it from the rest of life’. As Iris Bell and colleagues put it in a discussion of the research relevant to a new

model for primary health care: “The reductionist approach to science is valuable (but) it fails to reflect the way the real world operates”.<sup>19</sup> Which is perhaps why as Roy Porter reflected in the quotation in Chapter 3, despite the myriad ways in which science continues to advance, “Few people today feel confident, either about their personal health or about doctors, health-care delivery and the medical profession in general”.<sup>13</sup>

The medical research culture must change if it is to promote science for understanding alongside science for manipulation. Medical scientists might argue that the myriad advances in science do allow us to understand; to understand what goes wrong when disease affects us, and what to do about it. But it is probably fair, and more accurate to say that science allows us to *describe* what goes wrong so that we may do something about it, but not necessarily to *understand* it. It allows us to know what to do to correct the fault, but it does not help us to understand the mixed dynamics of the illness-disease-sickness process, nor of the healing process.

A change in the medical research culture that promotes this level of understanding and the health care practices that it permits will not come easily. The biomedical paradigm is so powerful and the model so successful that it is almost impervious to change. The plausibility construct or world view that sustains them is not conducive to change. Its materialist perspective encourages mechanistic solutions. “World views and the values placed on different health outcomes are closely related. Thus the values that underlie medical care shape the scientific questions that researchers ask, the health outcomes they measure, and the interpretation of the results”—Iris Bell and colleagues again, reflecting the discussion in Chapters 10 and 11.

To develop research methods that study health-care processes that are holistic and integrative is even more difficult than studying diseases and treatments that are isolated from the rest of life. This is because, by definition they concern illness-disease-sickness that has multiple determinants (predisposing and causative factors), that affects the person as a whole (all aspects of their well-being), that has multiple outcomes (physical, psychological and social), and that involves a number of interventions (either as ingredients of the ‘black box’ or as separate and distinctive processes), which are individualised to the needs of the patient.

It is obvious from this scenario that research of this kind is asking far more profound questions than ‘what is wrong?’, and ‘what works?’ It is asking questions about the whole phenomenon of illness-disease-sickness within the narrative of human experience, of life. It is exploring new ways of thinking about disease and therapeutics. This may sound idealistic and impossibly challenging. It is challenging, but it is not impossible. And to a limited extent the challenge is being met, the methods are being explored, and it is beginning to happen.

This is too big a subject for me to do more than offer a few examples to illustrate it. General readers who do not have an interest in research may find the

next few pages heavy going, and may prefer to skip to the Conclusion at the end of the chapter.

### 1. RESEARCH POLICY

Based on work by Trisha Greenhalgh, Professor of Primary Care Research, University College, London, writing in the *British Medical Journal*<sup>20</sup>:

The narrow focus of research policy and research commissioning is manifestly inadequate and inappropriate to health care in the real world: “Research policy is currently powerfully shaped and constrained by talk of the knowledge based economy and the contribution of high technology innovation to UK plc. This discourse has repositioned the core business of primary care research as running a ‘population laboratory’ for large scale epidemiological studies, preferably with a pharmacological component. Such studies are important but they are not the whole story.” Research initiative in general practice (which might reveal more of the story) is burdened by “the creeping institutionalisation and regulation of research. Epidemiology’s unanswered questions demand large scale collaborative studies that can be undertaken only within a complex research infrastructure. Non-epidemiological questions relevant to primary care (for example, on the humanistic and social dimensions of illness and healing) are currently defined as a lesser form of science for which only B-list funding and publication outlets are available.”

### 2. EXPLORING ILLNESS: INTERPRETIVE MEDICINE

These quotations are taken from a paper by Joanne Reeve proposing ‘interpretive medicine’ as a better framework for the generalist care that must be the foundation of good clinical practice. It is “the critical, thoughtful, professional use of an appropriate range of knowledge in the dynamic, shared exploration and interpretation of individual illness experience, in order to support the creative capacity of individuals in maintaining their daily lives.”<sup>21</sup>

The holistic and integrative ideal in medicine is best, if imperfectly, represented by general practice. Other disciplines, such as geriatric medicine and palliative care and some aspects of mental health care, also represent this generalist ideal. But it is threatened by the evidence based approach which has strayed from its founders’ intention that evidence should be submitted to the judgement of clinical relevance, and become focused on “hierarchies of evidence (that) privilege knowledge from what some consider to be a narrow methodological perspective.” The effect of this is to narrow the scope of the generalist’s perception of the patient. “The disadvantages of constrained protocol-driven care are recognised by the profession; but still form a new formative normative framework for clinical practice.” This militates against generalism, which “is more than disease-focused care delivered in a community setting. It is a different approach to understanding and addressing health and illness. (It) describes a

philosophy of practice which is person, not disease, centred; continuous, not episodic; integrates biotechnical and biographical perspectives; and views health as a resource for living and not an end in itself.” The generalist approach is essential to address growing concerns about the inefficiency, ineffectiveness and inequity of fragmented health care, and to promote an understanding of “specific events in their broader context, integrating biomedical evidence with a reflexive and interpretive approach that acknowledges, the complexity of individual human experience.”

### 3. SETTING RESEARCH PRIORITIES: A LAYMAN’S EXPERIENCE

This is a personal view published in the *British Medical Journal*.<sup>22</sup> The author, Lester Firkins, is a former banker who became involved in the world of medical research, specifically clinical trials, because of his role in a patients’ charity concerned with Creutzfeldt-Jakob Disease (CJD) which had claimed the life of his son. When he attended a consumer workshop on clinical trials for CJD he “assumed that this was what always happened in planning clinical research; it seemed natural and made sense.” He was surprised to discover however, that “the views of patients, their families and even clinicians are rarely sought when research priorities are being decided,” and that his later involvement as co-chairman on the steering committee for a CJD research project was “an example of ‘cutting edge’ involvement of lay people in clinical research.” Whereas to him it had seemed “a normal and sensible thing to do: who else other than someone closely involved with the disease could help with some important elements in the design of the trial?” In banking an attempt would automatically be made to research customers’ needs before packaging a new product.

His experience taught him that unpleasant competition for academic status and fiefdoms must not be allowed to override patients’ interests in research planning and funding; and that involvement of patients and their professional and lay carers should be normal and welcome in the shaping of clinical research, and knowledge about and participation in good clinical trials should be a normal feature of citizenship.

### 4. A CIRCULAR MODEL FOR RESEARCH

Presumably the kind of participation described above would be a component of the circular model of evaluation of complex interventions recommended by Harald Walach and colleagues.<sup>23</sup> This is proposed as an alternative to, and an improvement upon the ‘hierarchical’ method for evaluating complex interventions. All medical interventions when they are applied in the real world are in effect, as we have seen, complex interventions; if only because they inevitably include contextual and placebo effects, even when they involve only one specific procedure, which is seldom the case anyway. The hierarchical research model has at its base

descriptive case studies, but at its apex, and as the final arbiter of efficacy, the blinded randomised controlled trial. This depends upon the assumption that only the specific effects of a treatment or procedure, attributable to an understandable mechanism are of clinical value. This we know to be a false assumption.

The circular model described in that paper is derived from the evolution of evaluation methodology in the social sciences “which has reached the consensus that only a multiplicity of methods used in a complementary fashion will eventually give a realistic estimate of the effectiveness and safety of an intervention. Rather than postulating a single ‘best method’ this view acknowledges that there are optimal methods for answering specific questions, and that a composite of all methods constitutes best scientific evidence. Experimental methods that test specifically for efficacy have to be complemented by observational, non-experimental methods that are more descriptive in nature and describe real-life effects and applicability.” The authors quote the synthesis of different ways of knowing described by Gabbay and le May as the ‘mindlines’ used in decision making by general practitioners, as an empirical example and justification for this model.<sup>24</sup> (See Chapter 10, ‘Ways of knowing’.) “Many patients recover because of complex, synergistic or idiosyncratic reasons that cannot be isolated in controlled environments (trials). . . . By conceptualising evidence as circular we can highlight the fact that sometimes the ‘best’ evidence may not be attributional, objective, additive or even clinical.”

## 5. EVALUATING LARGE SCALE AND COMPLEX INTERVENTIONS

In fact it is not unusual that large scale healthcare interventions are introduced without clear evidence that benefits outweigh costs and harms. This was pointed out in a debate about the merits or otherwise of such a process in the *British Medical Journal*.<sup>25</sup> Bernard Crump argues that it can be appropriate to do so when explicit evidence is hard to come by; particularly in complex interventions that involve the behaviour of people and systems and that are just not susceptible to evaluation by the yardsticks that have been developed for narrower biomedical interventions. He, too, argues, as do Walach and colleagues vis-à-vis the social sciences, “We need to learn from other scientific sectors to broaden our understanding of evidence.” He is not suggesting an uncritical approach to such interventions, far from it, but a process for developing programmes of improvement that “builds on feedback on intermediate outcomes and will allow for adjustment of the intervention as the implementation takes place.” He recommends combining this with the ‘generative’ approach that takes account of the mixed dynamics of the therapeutic process and requires a deep appreciation of contextual factors, using a combination of qualitative methods (descriptive, observational, narrative) and quantitative methods (measur-

ing what it is possible and appropriate to measure).

The other protagonist to this debate, Seth Landefeld, argues that on the contrary the evidence should be compelling if well intended interventions are not to fail, perhaps cause harm, and cost dearly. He is doubtful that observational studies provide sufficient justification. But he warns that evidence should only be accepted, and interventions put into practice “carefully, because the effects of interventions may vary among patients, providers, and medical care environments, which often differ from those in studies that establish efficacy.” Which actually seems like an argument for the circular, iterative and generative approaches that others recommend.

## 6. MULTI-DISCIPLINARY INTEGRATIVE CARE

In a study from Denmark five conventional practitioners (neurologist, occupational therapist, physical therapist, psychologist and nurse) and five complementary practitioners (acupuncture, nutritional therapy, classical homeopathy, craniosacral therapy and reflexology) explored the possibilities of collaboration in the care of patients with multiple sclerosis (MS).<sup>26</sup>

The project’s core question was—‘Is it possible to improve treatment outcomes in people with MS by developing a model for bridge-building between conventional and alternative practitioners, and thereby facilitate and integrative treatment process at the patient level?’ The study is particularly interesting, and ambitious, because it brings together practitioners with, effectively, ten different theoretical and practical approaches to patient care. The basis for the dialogue (IMCO) was the four parameters—Intervention (what does the practitioner do together with the patient?), Mechanism (how do the process and context of treatment achieve the outcome?), Context (the motivation, attitudes, personal resources, insights and expectations that the patient brings to the process), and Outcomes (what physical, emotional, psychological and social benefits are expected and achieved by the intervention?). The definitions in parenthesis are my paraphrase.

The study did not set out to evaluate the outcome of multidisciplinary integrative care of this kind, but to explore its feasibility and the means by which it can be achieved. The study process (four seminars with preparatory work) was not easy, and common objectives in terms of outcomes were very difficult to agree. But eventually the ten practitioners “developed a mutual understanding of the different treatment models; began to think as a team; developed a mutual communication platform based on trust; and developed a platform for collaboration with the researchers.”

The authors conclude, “Creating bridges between fundamentally different ways of conceptualising diseases, curing and healing, simply takes time. However, collaboration is possible when focusing less on singular treatments and more on the primary target of optimising the treatment of each unique individual.”

## 7. INVESTIGATING 'WHOLE PERSON' APPROACHES

Iris Bell and colleagues emphasise as I have done that Integrative Medicine is not the same thing as complementary medicine (CAM) but “a comprehensive primary care system that emphasises wellness and healing of the whole person”.<sup>19</sup> Nevertheless, they go on to say that, “As it evolves, truly integrative medicine also depends for its philosophical foundation and patient-centred approach on systems of CAM that emphasise healing the person as a whole (e.g., Traditional Chinese Medicine, Ayurvedic Medicine, and classical homeopathy). These CAM systems diverge the most in philosophy, diagnosis and treatment from conventional medicine, and thus remain marginalised. As a result, clinicians and researchers often break off parts of these CAM systems from their original contexts to fit a few of the smaller pieces into the dominant model of conventional care and medical research. For example, numerous studies have investigated the efficacy of acupuncture for various Western disorders, but virtually no studies examine the effectiveness of the sum total of Chinese medicine as practiced. It is a testable hypothesis that the effect sizes of the full treatment program could be much larger and more clinically significant if the entire Chinese medicine treatment program were studied as used.”

### A THOUGHT EXPERIMENT

Only two of these examples of lateral thinking around the subject of research are directly related to complementary medicine (CAM), but they are all relevant to the particular challenge that is presented by the role of CAM, and any expanded role for CAM, within integrative health care. Here is a thought experiment that supposes the large scale introduction of a potential health care improvement for which there is not compelling evidence (example 5), but which could generate, or of course fail to generate such evidence.

The 2010 UK coalition government proposed that an £80 billion (€94 billion, \$124 billion) budget should be entrusted to general practitioners to commission services from other health care providers. Suppose that all 500 of the GP consortia expected to manage this budget, if it is equally distributed, were required to commit 0.1% of their share of the budget to integrating complementary medicine into primary and secondary care. Or if that seems too extreme, suppose that 0.0002% of the total budget is allocated to a 20% cohort of consortia, 100 of them, for that purpose. In either case each consortium committed to the task would have £160 000 (€187 000, \$247 000) to spend per year. The object of the exercise is to improve the health and well-being of their patients and to reduce the burden (of time, cost and stress) on themselves and their practices and the other services they would normally commission by the informed and discriminating use of complementary medicine; a similar exercise to that undertaken in the Glastonbury Project (Chapter 16). It would be a new exercise in interprofessional

care. It would require consortia:

- Get to know the complementary practices in their area.
- Understand and appraise their potential contribution to patient care—but not to learn their therapeutic methods (example 6).
- Learn from patients' experience of using complementary medicine (example 3).
- Select therapists (Chapter 19).
- Learn to collaborate (Chapter 19).
- Negotiate payment.
- Establish proper communication and continuity.
- Audit the process and its outcomes.
- Apply all appropriate ways of knowing (Chapter 10) to inform and develop their practice 'mindlines'.
- Incorporate research from formal trials with these other sources of knowledge in a circular process of evaluation (example 4) that comprehends the effectiveness of the complementary approaches as a whole rather than isolated bits of their respective black box (example 7).

This need not actually be a hugely time consuming or demanding task. It might even be enjoyable and liberating.

### CONCLUSION

*Medical knowledge is not knowledge acquired primarily for its own sake (but) for a specific purpose – the care of the sick.<sup>1</sup>*

Medical science and the study of health care delivery are already developing methods of enquiry and suggesting outcomes that justify a radical reappraisal of medical thought and practice. Subtle therapeutic methods that stimulate self-regulation and self-healing, and the contextual and 'meta-organic' factors that contribute to these have already achieved significance and importance in our understanding of the dynamics of health care. And their application is a widespread and insistent reality of contemporary medicine. Wider and more formal and systematic adoption and integration of these methods and of the precepts they exemplify promise health gains and economic benefits that are too great to ignore. If the promise is to be fulfilled, and it must certainly be tested to be sure that it can be, medical science must redirect its biomedical gaze towards these more holistic horizons. And that redirection of its gaze will require that it is more willing to adopt ways of looking at illness-disease-sickness, and at health care and healing that are far more flexible and versatile than the 'hierarchy' of evidence has hitherto permitted. Medical science must acknowledge that there are ways of knowing and things to be known that exceed the scope of its presently dominant paradigm. The examples given in these pages point the way.

Science, the systematically organised expression of our desire to know the world truly, admits to no

boundaries. But medical science is an applied science. As a doctor I am guided in my practice as much by an awareness of what I should not do as of what I should do. There are questions that I must ask, and questions that I must not ask unless the patient invites them, at least implicitly. There are insights that I must not offer unless and until the patient is ready to receive them; things I must not say because they would be inappropriate, impertinent or unkind. There are procedures I must not perform without the patient's consent; prescriptions I must not make unless they are really needed and will be tolerated. This often requires great sensitivity, discretion and restraint. In other words I have a repertoire of knowledge and skills, and personal attributes, which must always be subordinated to my compassionate understanding of the person in my care and the context of that particular therapeutic encounter. It must be appropriately applied.

The application of science in medicine must be similarly discriminating, and always have a *person* in its gaze, even when it is a molecule that is the precise focus of attention. This is a shared responsibility between the clinician and the scientist. Scientists must fully understand the implications that the application of their science will have for the therapeutic process, the healing relationship. They must not promote its application simply out of their scientific enthusiasm for its possibilities, just as I must not impose some treatment on a patient simply because of my enthusiasm for that particular drug or procedure, or therapeutic theory. And the clinician must not adopt a scientific advance just because it becomes available. It must never be true, to misquote David Haslam again, that we use the medical science because the medical science is what we use. We must never be tempted to use a laboratory test just because it has become a cheaper and easier way of managing a patient if it does not help us to understand that patient's predicament truly; particularly if it becomes a substitute for listening to the patient carefully. And I mean carefully. Clinicians must never succumb to the lust described by D.H. Lawrence and quoted by David Horrobin<sup>4</sup>:

*When I went to the scientific doctor  
I realised what lust there was in him to wreak his  
so-called science on me  
and reduce me to the level of a thing.  
So I said: Good morning! And left him.*

There must be a dialogue between clinicians and scientists that ensures that what clinicians really need to know, or really need to have available to them, is translated into an agenda for the scientists. And that what scientists have to offer can be really usefully applied in clinical practice. The same principle applies to other fields of applied science, of course. And it begs the question—When should this dialogue begin? I suspect that to be truly fruitful it must begin at quite an early stage in a common educational pathway.

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